DOCUMENT RESUME

ED 364 011 EC 302 580

| | |
|---|---|
| AUTHOR | Kupper, Lisa, Ed. |
| TITLE | Parenting a Child with Special Needs: A Guide to Readings and Resources. |
| INSTITUTION | Interstate Research Associates, McLean, VA.; National Information Center for Children and Youth with Disabilities, Washington, DC. |
| SPONS AGENCY | Special Education Programs (ED/OSERS), Washington, DC. |
| PUB DATE | 93 |
| CONTRACT | H030A00002 |
| NOTE | 25p. |
| AVAILABLE FROM | Interstate Research Associates, NICHCY, P.O. Box 1492, Washington, DC 20013-1492 (individual subscriptions free). |
| PUB TYPE | Reference Materials - Bibliographies (131) -- Collected Works - Serials (022) |
| JOURNAL CIT | NICHCY News Digest; v3 n1 1993 |
| EDRS PRICE | MF01/PC01 Plus Postage. |
| DESCRIPTORS | *Child Rearing; Coping; *Disabilities; *Emotional Adjustment; Family Problems; Information Needs; *Information Sources; Long Range Planning; Organizations (Groups); Parent Child Relationship |

ABSTRACT

This special issue focuses on needs of parents of children with disabilities. In the first article, "You Are Not Alone," Patricia McGill Smith considers the emotions that many parents of exceptional children experience and offers a perspective for living and coping with the impact of disability upon the family. The second article, "The Unplanned Journey," by Carole Brown and others, explores areas in which parents often need information and identifies 61 potential resources. This article addresses such issues as: adjusting to life with a disabled child, accessing information and services, supporting the needs of the family, finding child care, addressing financial concerns, working with professionals, and planning for the future. The issue concludes with a bibliography of 60 print resources organized around critical issues, as well as a list of 60 print resources on specific disabilities. Thirty organizations that can provide families with additional information, support, or referral are also listed. (DB)

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# Parenting A Child With Special Needs: A Guide To Readings And Resources

Volume III, Number 1, 1993

NICHCY News Digest

National Information Center for Children and Youth with Disabilities
Washington, DC

*When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and may not know where to begin their search for information, assistance, understanding, and support. This* **News Digest** *has been developed expressly to respond to the information needs of parents — those who have just learned their child has special needs and those who have lived with this reality for some time but who have reached a transition point where they need new information or renewed support. This issue provides a starting point for families in their search for information and resources. We hope that it will also be useful to professionals who work with families who have a child with a disability, helping them to understand how having a child with a disability can affect the family and providing them with a ready resource to share with the parents with whom they work.*

*In the first article, "You Are Not Alone," Patricia McGill Smith speaks candidly to parents about the emotions that many parents of exceptional children experience and offers a perspective for living and coping with the impact of disability upon the family. The second article, "The Unplanned Journey," delves into the areas in which parents and families often need information and offers suggestions about potential resources. Included in this article are discussions of such issues as: adjusting to this new life, accessing information and services, supporting the needs of the family, finding child care, addressing financial concerns, working with professionals, and planning for the future. This* **News Digest** *concludes with an extensive bibliography of print resources organized around these critical issues, as well as a list of print resources on specific disabilities. Organizations that can provide families with additional information, support, or referral are also listed.*

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## You Are Not Alone: For Parents When They Learn That Their Child Has A Disability

*by Patricia McGill Smith*
*Executive Director*
*National Parent Network on Disabilities*

If you have recently learned that your child is developmentally delayed or has a disability (which may or may not be completely defined), this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated — and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help yourself through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

### Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of *denial* — "This cannot be happening to me, to my child, to our family." Denial

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## *You Are Not Alone*

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rapidly merges with *anger,* which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of *grief* and inexplicable *loss* that one does not know how to explain or deal with.

***"It is important for parents . . . to know that they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance."***

*Fear* is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child's future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?" Then other questions arise: "Will she ever learn? Will she ever go to college? Will she have the capability of loving and living and laughing and doing all the things that we had planned?"

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is *guilt* — guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?" or "Why my child?", many parents are also saying, "Why has God done this to me?" How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?" One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

*Confusion* also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's disability.

*Powerlessness* to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

*Disappointment* that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

*Rejection* is another reaction that many parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child — a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that *they are not alone.* There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

### Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a disability is a blessing."

I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a boy with mental retardation.

My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent-Helping-Parent Programs. The National Information Center for Children and Youth with Disabilities (NICHCY) has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to or call NICHCY to get that local information.

## Talk with Your Mate, Family, and Significant Others

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength. Understand that you each approach your roles as parents differently. How you will feel and respond to this new challenge may not be the same. Try to explain to each other how you feel; try to understand when you don't see things the same way.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life — your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

## Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another may be a good friend or a counselor. Go to those who have been a source of strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

## Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Even though it may not seem possible, good things will continue to happen each day. Worrying about the future will only deplete your limited resources. You have enough to focus on; get through each day, one step at a time.

## Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the word.

## Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request accurate information. Don't be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports. If you are not a naturally organized person, just get a box and throw all the paperwork in it. Then when you really need it, it will be there.

## Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials and, sometimes, because of their professional manner. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

## Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how they are feeling. The strongest fathers of children with disabilities whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

## Learn to Deal with Natural Feelings of Bitterness and Anger

Feelings of bitterness and anger are inevitable when you realize that you must revise the hopes and dreams you originally had for your child. It is very valuable to recognize your anger and to learn to let go of it. You may need outside help to do this. It may not feel like it, but life will get better and the day will come when you will feel positive again. By acknowledging and working through your negative feelings, you will be better equipped to meet new challenges, and bitterness and anger will no longer drain your energies and initiative.

## Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is, truly, always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things pointed out to me was that she was a very healthy child. She still is. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised. Focusing on the positives diminishes the negatives and makes life easier to deal with.

## Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

## Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

## Find Programs for Your Child

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. NICHCY's *State Resource Sheets* list contact persons who can help you get started in gaining the information and assistance you need. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

## Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

## Avoid Pity

Self-pity, the experience of pity from others, or pity for your child are actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

## Decide How to Deal With Others

During this period, you may feel saddened by or angry about the way people are reacting to you or your child. Many people's reactions to serious problems are caused by a lack of understanding, simply not knowing what to say, or fear of the unknown. Understand that many people don't know how to behave when they see a child with differences, and they may react inappropriately. Think about and decide how you want to deal with stares or questions. Try not to use too much energy being concerned about people who are not able to respond in ways you might prefer.

## Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then you do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

## Remember That This is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or in less need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

## Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost universal among parents. In this article, there are many recommendations to help you handle feelings of separateness and isolation. It helps to know that these feelings have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

*Patricia McGill Smith brings much personal and professional experience to the national parent and disability movement. She is currently the Executive Director of the National Parent Network on Disabilities. She has served as the Acting Assistant and Deputy Assistant Secretary in the Office of Special Education and Rehabilitative Services, in the U.S. Department of Education. She has also served as the Deputy Director of NICHCY, where she wrote and first published* You Are Not Alone. *She has travelled to almost every corner of the United States, as well as internationally, to share her hope and experience with families who have a member with a disability. Ms. Smith has seven adult children, the youngest of whom has multiple disabilities. She also has a new member of her family, an adopted grandson, Sean, who has Down syndrome.*

# The Unplanned Journey: When You Learn That Your Child Has a Disability

*by Carole Brown, Samara Goodman, and Lisa Küpper*

The birth of a child with a disability, or the discovery that a child has a disability, can have profound effects on the family. In "You are Not Alone," the first article in this ***News Digest,*** Patricia McGill Smith offers the insights that she and others have gained through their own experience of having a child with a disability — the emotions they have had, the supports they have found, both within themselves and within their communities, and the means they have discovered of adapting to and living with the impact of disability upon the family. In this article, we will provide additional information to support the life cycle, health, and well-being of the family when a member has a disability. Knowledge is empowering, and when parents obtain the information they need, they often are empowered to help, support, and maintain the entire family, including the child with the disability, siblings, grandparents, and themselves.

It is with a great deal of humility that we are even attempting to describe what the future may hold for you and your family. On the one hand, we want you to be as prepared as possible so you can negotiate the challenges which may await your family. On the other hand, we recognize that individual variation and differences are the rule when a child has a disability. Researchers often base their findings on group data — what happens to the majority of people in a circumstance. However, what might be "true" in a research sense may not be at all true for your family. For example, many years ago Carmen Ramirez and her husband, parents of a young child with a disability, decided not to speak in Spanish with their son, based upon research that advised against a bilingual approach when a child has a disability. Today Carmen regrets that decision; her son is now at a disadvantage within his own family, where Spanish is a primary language for many members.[1]

Therefore, while we hope this article will guide you to sources that are helpful, take from our discussion only what you need.

## The Journey

> *Growth is endless and our lives change and change us beyond anticipation. I do not forget the pain — it aches in a particular way when I look at Jessy's friends (her paid companions), some of them just her age, and allow myself for a moment to think of all she cannot be. But we cannot sift experience and take only the part that does not hurt us.*[2]

No parent wants his or her child to be sick, disabled, or harmed in any way. It is not an experience anyone expects to have; rather, it is a journey that is unplanned. The terrain families must travel is often rough in places. The stress families may experience because of their child's disability may be the most difficult of their lives and often affects important aspects of family functioning.[3] And yet, the majority of families are able to find the strength within themselves and among their circles of support to adapt to and handle the stress and challenges that may accompany their child's illness or disability.

Many parents have described the progression — and pendulum — of feelings they experienced upon learning that their child has an illness or a disability. Patricia McGill Smith touched upon many of these emotions in her article — shock, denial, grief, guilt, anger, confusion. Not all parents will experience all of these emotions.[4] Some families feel that they experience no greater sorrow than any other person, while others feel a sense of sorrow that is never completely resolved.[5] Still others feel that these reactions are not necessarily experienced sequentially but may, in fact, occur repeatedly, precipitated by various life crises and turning points.[6] Usually the first crisis is when a child is initially identified as having a disability. Other crises may occur during times of transition, such as (1) at school-entry age, (2) during adolescence, (3) when leaving school, and (4) when parents grow older.[7]

The type of emotions parents experience, as intense and overwhelming as they may be, are also normal and acceptable. Parent Rhonda Krahl writes that "these feelings and others are a necessary part of the adjustment process."[8] However, through whatever means of adjustment each parent finds — and these will vary from person to person — stability does return, both to the individual and to the family. Tobi Levin points out, "Most parents eventually go from asking 'why' to 'what do I do now?'"[9] At this point, parents may begin to search for needed information. Many parents also report feelings of personal growth that are often, in retrospect, astounding to them. One mother, describing the first two years of life after the birth of a child with spina bifida, said:

> *I can now admit that having Laura is mostly a blessing...much of the experience has been positive, challenging, and rewarding, and I have grown as a person in ways I may not have without her...In fact, the past two years have changed me for the better in just about every way. Nevertheless, I still don't want to be the mother of a handicapped child. But I am Laura's mother, I love her deeply, and that makes all the difference.*[10]

Taken together, the many suggestions and insights offered by parents who have lived for years with the experience of disability in the family can provide parents who are new to the experience with much guidance and support. The remainder of this article will outline many of the ways that parents have helped themselves and those they love adjust to living with and caring for a child with special needs.

## Accessing Information and Services

One of the first things you can do that may prove enormously helpful, now and in the future, is to collect information — information about your child's disability, about the services that are available, and about the specific things you can do to help your child develop to the fullest extent possible. Collecting and using the information available on disability issues are critical parts of being a parent of a special needs child. Fortunately, there is a great deal of information available on many disabilities and many disability issues. Parents often report, however, that at first they did not know where to begin searching for the information they needed.

## Joining a Group

Much of the information that will be helpful to you is in the hands, heads, and hearts of other parents like yourselves. For this reason, it is worthwhile to join a parent's group, which can offer you the opportunity to meet other people with children who have disabilities. Some groups are organized around one particular disability (e.g., cerebral palsy, Tourette syndrome, Down syndrome), while other groups draw together parents who, irrespective of the disabilities of their children, have similar concerns, such as daycare, transportation, coping, or finding out about and supporting special education in their community. Within each of these groups, information, emotional and practical support, and common concerns can be shared. The power of this mutual sharing to combat feelings of isolation, confusion, and stress is a consistent thread running throughout the literature written by and for parents.

> *I belonged to [a] group of moms and from them came the reassurance that I was going to be okay...Here I could let it all hang out. We talked about resentment at mismanaged pregnancies and birthings; frustration with case managers that didn't manage, doctors who didn't listen, and spouses who didn't help. This was a safe place to express my feelings where the listener would really understand and wouldn't think I was "falling apart" or "still grieving" or "not handling it too well." We laughed together. We cried together. Even though our children had different disabilities, we were alike: Alike in our anger, alike in our fear, alike in our hope.*[11]

There are many ways to identify a parent group in your area, including asking your family doctor, calling a local school, contacting the state or local parent training and information (PTI) center, and looking in the telephone directory. NICHCY's *A Parent's Guide to Accessing Parent Groups* describes a process for finding (or starting) a group suited to your particular interests and needs; NICHCY also makes available a *State Resource Sheet* for each state, which provides information about parent groups within the state. These materials are available free of charge.

## Reading Books Written for and by Parents

You may also find it worthwhile to read many of the excellent books that are available on disability issues. A good starting point for identifying the book or books most suited to your family's needs is *A Reader's Guide for Parents of Children with Mental, Physical, or Emotional Disabilities* by Cory Moore.[12] This book includes annotated descriptions of more than 1,000 books and articles on disabilities. There are also many shorter bibliographies available. Worthwhile suggestions for reading can come as well from talking to a local librarian, your child's teacher, or other involved professional; contacting a national, state, or local disability group; talking to other parents of children with disabilities; or by contacting NICHCY.

You may also wish to obtain information about your child's disability and other medical issues, such as how to choose a doctor and obtain needed medical services. NICHCY's *A Parent's Guide to Doctors, Disabilities, and the Family* is a useful beginning point, for it contains many suggestions for finding and interacting with doctors when there is a child with a disability involved.

Many children, however, have problems that are difficult to diagnose. Parents may be told, "It's nothing and will go away. You're overreacting. It's a stage."[13] These parents "will need stamina, patience, and unusual resources to find out what is wrong with their child. That label may not come easily, but if parents don't pursue it, most likely no one else will."[14] If you are having trouble obtaining a diagnosis for your child, one mother who searched for years for a diagnosis of her son's condition recommends that you:

- keep accurate records that can provide a clue to the problem;
- talk to others (nurses, doctors, teachers, pharmacists, parent groups, local medical board) who may be able to offer valuable information, leads, or assistance;
- research the problem on your own, through reading books and articles, conducting computer searches, and utilizing interlibrary loan materials; and
- trust your own observations and evaluate new information based upon your own knowledge of the child.[15]

For those who have an early, accurate diagnosis of their child's disability, the search for information is generally easier. There are many books available that look comprehensively and in-depth at one disability. Typically, these books describe the disability, discuss the family's adjustment, identify medical issues, provide guidance about dealing with medical practitioners and developing appropriate therapy programs, discuss daily life, describe how a child with that disability might be expected to develop, and address educational implications and legal issues. A short list of such books, organized by specific disabilities, is provided in the resource section of this ***News Digest***.

## Accessing Services

The search for available services is a challenge for families and one that continues as the child's needs change. Most of these services are made available because of legislation at the federal and state levels. Because a core of laws affects the ser-

vices that are available, how and to whom those services are provided, and the process of obtaining the services, it becomes essential for families to be informed about their legal rights. Many of the guides listed in the references and resources section of this ***News Digest*** provide overviews and guidance in relation to the legal and educational rights of children and youth with disabilities. For a quick read on the core of federal laws governing the educational rights of children and youth with disabilities, NICHCY offers *The Education of Children and Youth with Special Needs: What do the Laws Say?* and *Questions and Answers About the IDEA.*

Typically, there are many services available within communities, districts, and states to assist you in meeting the needs of your child with disabilities and your family. For families with a young child — birth through the third birthday — with disabilities, it may be critically important to access *early intervention services*, which are designed to identify and treat developmental problems as early as possible. For school-aged children with disabilities, *special education* and *related services* can be important factors in addressing a child's educational needs.

***Early intervention services.*** Early intervention services are designed to address the needs of infants and toddlers with disabilities as early as possible and, as such, can range from feeding support from a nutritionist in a hospital to developing a complete physical therapy program for an infant with cerebral palsy. However, these services are not just for the child with special needs. When framing the law describing early intervention services, Congress recognized that families are central in a young child's life. Therefore, the family's priorities, concerns, and resources have become the foundation for planning services for infants and toddlers with disabilities. The plan that is developed through this process is called an Individualized Family Service Plan (IFSP).

Parents, too, can benefit from early intervention services; as full members of the team developing the program for their child, they can learn skills that may be useful for a long time — skills in decision-making, planning, being of support to others, and influencing the policy-making process in their communities. Giving testimony before the Senate on the value of early intervention services, one mother stated:

> *...Children, and the families that love and nurture them, have needs that cannot be easily compartmentalized. Especially in early childhood, a family's priorities may be rapidly changing and may cross over numerous "systems" boundaries. As I recall the hours of early intervention our daughter received, the most valuable lessons were based on recognizing her worth as an individual, taking into account our abilities, as her parents, to seek out ways to encourage her growth and development and, finally, reaching out to other families with children, with or without disabilities, to participate in mutually supportive relationships that meet the needs of each individual in the family as well as the community.*[16]

***"Typically, there are many services available within communities, districts, and states to assist you in meeting the needs of your child with disabilities and your family."***

The services themselves are offered through a public or private agency and are provided in different settings, such as your home, a clinic, a neighborhood daycare center, a hospital, or the local health department. Initial evaluation and assessment of your child will be provided free of charge. Services may also be provided at no cost, although this may vary from state to state; some states charge a "sliding-scale" fee based upon what you, as parents, earn.

It is important to know that some states are still in the process of developing these services. Therefore, depending upon the state in which you live, early intervention services may be fully available or may still be in the process of developing. Every state now has developed a central directory of early intervention services, and many states will provide service coordinators to help parents find services for their child. Your family physician, hospitals, or a specialist working with your child can also be important resources of information, as can the NICHCY *State Resource Sheet*, which identifies the name and telephone number of your state's contact person for programs for infants and toddlers with disabilities.

***Special education and related services.*** Through the mandates of a number of federal laws — most notably, the Individuals with Disabilities Education Act, or IDEA (formerly known as the Education of the Handicapped Act, EHA, or Public Law 94-142) and Section 504 of the Rehabilitation Act of 1973 — each eligible child with special needs is guaranteed a free appropriate public education designed to address his or her unique needs. This education is planned by a multidisciplinary team, including the parents of the child. In order to benefit from this special education, the child may also need to receive a variety of related services (e.g., transportation assistance, occupational and physical therapy, audiology, school health services, speech-language pathology, and psychological services). These, too, are to be provided by the school to eligible children at no cost to their families.

Thus, as parents, you are key participants in the team that determines what type of special education your child will receive, as well as what related services are necessary to help him or her maximize the benefits of that special education. Together, the members of your child's team develop an Individualized Education Program (IEP), which states in writing the educational program that is planned for your son or daughter, including learning goals and the educational services that the school system is to provide.

There are many books that can be of particular usefulness if you are seeking to

**Information from NICHCY**

- *A Parent's Guide to Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities (1992)*
- *Questions and Answers About the IDEA (1993)*
- *Related Services for School-Aged Children with Disabilities (1991)*

understand and access special education services; several have been listed in the resources section of this ***News Digest.*** Additionally, many of the parent guides mentioned throughout this issue discuss how to access these services and advocate for the legal and educational rights of your child. Material is also available from NICHCY to explain the special education process (see the box above).

## Supporting and Empowering the Family

### Parents as Individuals and as Partners

There are a number of vital factors within each family which will influence its ultimate well-being. One is the emotional and physical health of each parent individually. Because it is generally the parents who confront the issues associated with their child's disability (e.g., dealing with medical practitioners, caring for the child), while simultaneously trying to maintain the household (e.g., holding down jobs, shopping, cooking, cleaning up, taking care of other children), it is not surprising that many parents of children with disabilities report times of feeling overwhelmed. It is, thus, very important for you, as parents, to take some time to care for *yourselves* as individuals: getting enough sleep, eating regular meals, trying to exercise every day, even if it is just taking a short walk.[17] As one mother relates:

> *I would sometimes retreat to my "tower" and pretend that I had no responsibilities other than to amuse myself with a good book or a soothing tape. The respite usually didn't last more than a half hour, and it was never enough, but it helped me break the "martyr" pattern of thinking I was required to live and breath only for my children.*
>
> *In those brief moments of quiet reflection I could renew my sense of self and remember that I was important, too; that I was Kate, a person, with lots of abilities and interests that did not all coincide with my role as Mommy. I came to realize that a little selfishness is not a bad thing. If I could enjoy myself more, I could enjoy my children more.*[18]

This sentiment is echoed throughout most of the literature written by parents. As Rhonda Krahl remarks, "What your child needs most is a healthy, loving parent. You can give him that by taking care of yourself."[19]

Many families will be single-parent families, but for those who are not, the relationship *between* the parents is a factor that can influence the family's well-being. When the parents' relationship is a strong and supportive one, it enriches family life for all members. Conversely, when there are problems in the relationship, the tension affects the rest of the family as well. This is stating what most of us already know, as is saying that marriages undergo change with the birth of a child — any child. But when a child in the family has special needs, "the changes (in the marriage relationship) will be greater and more demanding."[20] For a number of reasons, parenting a special needs child can create stress and conflict between the parents. For one, fathers and mothers may react differently to the fact of the disability. Mothers typically respond more emotionally than fathers, who are apt to focus more on the future and the long-term concerns of the child.[21] At times, one parent may be actively experiencing grief and may feel alone if the other parent is unable to express his or her grief and sorrow.[22] At other times, decisions must be made about the child's care, and parents may not agree. And when all is said and done, the sheer demands of parenting can leave each partner exhausted and drained. "With all the time you must spend with and for your child, it's easy to forget to take time for your mate...You can easily lose track of what your mate is thinking, feeling or doing as you concentrate on keeping up with family routines."[23]

Much of the literature written by parents discusses ways for parents to protect their relationship. One point emerges again and again, and that is the importance of making time for each other: meeting for lunch, getting away for a few hours together, sharing an activity. "This isn't neglecting your responsibilities. If the relationship crumbles you will face even more duties. Taking time to preserve your relationship makes good, practical sense, even if something else has to suffer temporarily."[24] Talking to each other and really *listening* are also important — and conversations do not always have to revolve around the children in the family. Finding other topics to discuss can do much to revitalize parents and preserve intimacy between them. It is also important to recognize that there are times when one partner needs to have space. As Peggy Finston puts it, "We need to accept how our mate distracts himself or herself."[25] Sharing the duties of providing care is also necessary, although couples report that they often have to work hard at communicating in order to achieve the "we-ness" that goes behind teamwork. Many parents have found it is necessary and helpful to seek joint counseling. Through this process, they grew to understand each other's needs and concerns more fully and found ways of discussing and resolving their differences.

### Brothers and Sisters: The Sibling Story

We know from the experiences of families and the findings of research that having a child with a disability powerfully affects everyone in the family. This includes that child's brothers and sisters. Many authors and researchers have written with eloquence about how the presence



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of a disability affects each sibling individually, as well as the relationships between the siblings. Some books dealing with sibling issues are listed in the resources section of this document.

The impact, according to the siblings themselves, varies considerably from person to person. Yet there are common threads that run through their stories. For many, the experience is a positive, enriching one that teaches them to accept other people as they are. Some become deeply involved in helping parents care for the child with a disability, often assuming responsibilities beyond their years in terms of that individual's care and the maintenance of the household.[26] It is not uncommon for siblings to become ardent protectors and supporters of their brother or sister with special needs or to experience feelings of great joy in watching him or her achieve even the smallest gain in learning or development. Increased maturity, responsibility, altruism, tolerance, humanitarian concerns and careers, a sense of closeness in the family, self-confidence, and independence are among the other positive effects noted in siblings.[27]

In contrast, many other siblings experience feelings of bitterness and resentment towards their parents or the brother or sister with a disability. They may feel jealous, neglected, or rejected as they watch most of their parents' energy, attention, money, and psychological support flow to the child with special needs.[28]

The reaction and adjustment of siblings to a brother or sister with a disability may also vary depending upon their ages and developmental levels. The younger the nondisabled sibling is, the more difficult it may be for him or her to understand the situation and to interpret events realistically.[29] Younger children may be confused about the nature of the disability, including what caused it. They may feel that they themselves are to blame or may worry about "catching" the disability. As siblings mature, their understanding of the disability matures as well, but new concerns may emerge. They may worry about the future of their brother or sister, about how their peers will react to their sibling, or about whether or not they themselves can pass the disability along to their own children.

Clearly, it is important for you to take time to talk openly about your child's disability with your other children, explaining it as best you can in terms that are appropriate to each child's developmental level. As Charles Callahan remarks, "Information, even concerning a painful subject, is preferable to ignorance distorted by imagination."[30] Some of the books listed in the resources section under "Siblings" can help you open up the lines of communication and address the needs of your nondisabled children. As services for families grow, you may also find there is a support group available to your children, which can provide a forum for siblings to share their feelings with others in a similar situation and to exchange factual information about disability and illness.

## The Child with Special Needs

Much of how you raise your child with a disability will depend on your family's personal beliefs about childrearing, your child's age, and the nature of his or her disability. An important point to remember is that most of the regular child-raising issues will apply – children with disabilities will go through the usual childhood stages. They may not go through stages at the same age, at the same rate, or use the same words as children without disabilities, but they *are* children and kids are kids.

We, as parents, may believe that all children should be treated the same, but in practice that is usually not the case. Why? Because anyone who has been around children, even infants, knows they have different personalities and react differently to similar situations. We encourage and coax the shy child and set limits for the rambunctious one. We tell the loud ones to be quiet and the quiet ones to speak up. We offer different activities to the child who loves to paint than to the one who wants to play ball. Children just are not the same — but they should have the same opportunities.

Among their opportunities should be the chance to assume increasingly greater degrees of responsibility and independence. There may be many ways in which your child can help himself or herself or other members of the family, including doing chores around the house. You will need to consider what these activities might be, given your son or daughter's disabilities and capabilities. As you expect and encourage your child to assume responsibility, his or her sense of pride and competence will also increase. As Ivonne Mosquera remarks:

> *Even though I'm blind, even though it may take me a bit longer to do certain things, I can still do them...Once you accomplish a goal, you'll be the person who feels good about it. Whether or not other people congratulate you for it, you'll feel better, and you'll know that you did it because of you — because you never gave up.*[31]

***"As you expect and encourage your child to assume responsibility, his or her sense of pride and competence will also increase."***

Conversely, to not expect or encourage your child to contribute to self-care or household matters may send the message that he or she is not capable of helping. Dependence is fostered instead, as Teresa discovered with her daughter Betsy. "First, they were little things like turning on the bathwater. Then she wanted me to carry her instead of using crutches. She refused to even try using them. I couldn't make myself say no, yet I knew that somehow this was going too far."[32]

Of course, the nature and severity of your child's disability may affect how much he or she is able to participate in household duties and so on. Peggy Finston remarks:

> *The issue, then, for each of us is what is a "realistic" amount of normality to expect from our child? If*

*we expect too much, we run the risk of rejecting him as he is. If we expect too little, we will fail to encourage him to do the most he can with himself. There is no one answer for all of us, or even for all of us dealing with the same condition. The best we can do is to realize that this is an ongoing question that we need to consider.*[33]

Perhaps some of the most encouraging words for parents come from children who have disabilities, whose experiences and feelings are described in numerous books. One consistent idea they express is that when parents expect a child with a disability to develop his or her capabilities — whatever these may be — this empowers and strengthens the child. This sense of empowerment can be found, for example, in the dedication Tom Bradford wrote for his book about hearing loss; he dedicated the book to his mother "who never let me know that my hearing loss could have been a limitation."[34] Eli, a twelve-year-old whose stroke resulted in several physical disabilities, writes, "My friends and family helped me overcome my fears. They encouraged me to try everything, even if I was determined that I couldn't."[35] Fourteen-year-old Sarah says that, despite her artificial leg, "my parents sent me to a regular nursery school, to swimming lessons and camp — everything other kids did...I think my family's encouragement has a lot to do with the fact that I have such a positive attitude. They never sat me in front of the TV or stopped me from doing anything I wanted to try. They gave me a normal childhood."[36] Robert, who has cerebral palsy, remembers that his mother said to him one day, "Robert, why don't we focus on what you can do instead of what you can't do?" This was, he believes, "my biggest turning point — I took off like a rocket!"[37]

## Grandparents

Grandparents are often greatly affected by the birth of a child with a disability; the pain they feel may be two-fold — pain for their grandchild and pain for you, their own child. It is important to remember that they will need support and information, too, and that "the way you relate to them can create the setting for how they will help or not help you, or how they will deal with the child."[38] Some grandparents may have difficulty accepting their grandchild's disability, which is as normal as the stage of denial parents themselves may have experienced. Others will be a great source of help and support, and their involvement can benefit the nuclear family.[39]

Therefore, your parents and other members of the extended family need to be given opportunities to get to know your child as a person and not just a person with disabilities.[40] Allowing them to become involved with your child may also allow you some much-needed time away from the responsibilities associated with caring for a child with special needs.

## Child Care: From Babysitters to Respite Care

All parents, at some time, will probably seek child care. For families with a child who needs more supervision or specialized assistance, child care may be difficult to find – or feel comfortable with. Even if you do not work outside the home and do not need regular child care, you may benefit greatly from having child care on a periodic or even an ongoing basis; this will give you time to take care of personal matters, enjoy some leisure activity, or be relieved of the constant need to care for a child with a disability or chronic illness.[41] Indeed, families who use child care on a regular basis report that it "not only gave us something to look forward to but also broke time down into pieces we felt we could handle."[42] Child care, particularly following a crisis, may be an essential factor in maintaining your family's health, stamina, and equilibrium. The mother of a child with a chronic illness writes:

*The week that our family stayed at the beach was the most wonderful gift...for it gave us the opportunity to stand outside the situation and view it from a distance. It enabled us to review what had gone on before, to put things into perspective, to think and plan. We were also physically restored, and were able to go on with much more strength...caring for our daughter.*[43]

Basically, child care falls into several categories, ranging from the care provided by relatives, neighbors, or friends who help out, to babysitters, to the more specialized care provided through daycare facilities/providers, respite care services, and nurses/medical specialists. Each family will need to determine its own level of need at any given time. The type of child care you select will depend upon a number of factors, including the nature of your child's disability, the cost involved in the care, and the length of time for which the care will be provided. If your child requires more supervision or attention than normal but does not need specialized medical care per se, you might have a relative, family friend, or a responsible babysitter occasionally take care of your son or daughter with special needs.

***"You can help daycare providers by being as honest and direct as possible about your child's needs."***

Daycare also can be important for the well-being of children with disabilities, because it presents an opportunity for them to socialize with other children. Parents often want their child with disabilities to have the same opportunities as other children and have been disappointed to find that many daycare or preschool settings were not available or accessible to youngsters with disabilities. This kind of discrimination is now illegal. The Americans with Disabilities Act (ADA) calls for full access to daycare for children with disabilities. In some cases, the needs of a child will be such that a particular daycare provider or center may not be equipped to care adequately for that child. The law now provides for flexibility in these cases; often, parents will have to be resourceful to help a provider become equipped or knowledgeable about how to care for the

needs of a child or to find other sources of help.

You can help daycare providers by being as honest and direct as possible about your child's needs. It may also be helpful to let providers know how much their care is needed by and supportive to your child. The partnership between parents and daycare providers is very important, but it is especially so when the child has a special need. Research has shown that preschool and child care centers have the most success in integrating children with disabilities when staff accept and value diversity in the children they serve.[44]

Another option is *respite care*, a system of temporary child care provided by people familiar with the needs of children with disabilities. "Temporary" can range from an hour to several months, depending on the respite care provider and the needs and desires of the family. Many respite care providers have undergone specialized training and can knowledgeably care for children whose needs may range from close supervision to medical care. Respite care can be provided to infants, teenagers, or adults with special needs. In some cases, the respite provider may be able to provide care only for the child with the disability; in other cases, care may be available for siblings as well. Respite care generally differs from daycare in that it is not available on a daily basis to allow a parent to return to the work force.

During the past 10 years, more than 30 states have passed legislation for in-house family support services, including respite care.[45] Increasingly, respite care can be obtained through organizations that offer home-care or out-of-home services, either on an emergency basis or on a regular schedule. In many states, mental health agencies provide services which are either free of charge or priced on a sliding scale (according to parents' ability to pay). To find out more about the respite services available in your vicinity, seek out groups or professionals who work with children your child's age. The school system may be able to provide information, as may a local parent group. Other places to inquire include:

- Parent Training and Information Center;
- Disability organizations within the state;
- State Department of Mental Retardation;
- State Developmental Disabilities Council;
- State Program for Children with Special Health Needs;
- Departments of Health and Human Services, or Social Services;
- Department of Mental Health;
- State and local Departments of Education; and
- State Protection and Advocacy Agency.

Many of these organizations are listed in the telephone directory; NICHCY also makes available a *State Resource Sheet*, which lists telephone numbers and addresses for many of these programs or groups. Although many parents initially may feel reluctant to leave their child with special needs in the care of someone else, those who have tried it give ample testimony to its value in restoring their energy, sense of humor, and perspective.

## Working with Professionals: The Parent/Professional Relationship

Parent Cory Moore, speaking directly to professionals, writes:

> *We need respect, we need to have our contribution valued. We need to participate, not merely be involved. It is, after all, the parent who knew the child first and who knows the child best. Our relationship with our sons and daughters is personal and spans a lifetime.*[46]

Recognizing the central role of the family in a child's life, many service systems now provide assistance to parents and other family members using what is known as family-centered support principles.[47] Within this philosophy, the family's influence is recognized as primary, both because of its direct impact on the child's development and because the family serves as the link between the child and the outside world. Thus, you have the right to be fully informed and involved in decisions affecting your child and family.

Many of the books listed throughout this ***News Digest*** offer insight into how you might work together with professionals for the benefit of your child and family. The best relationships are characterized by mutual respect, trust, and openness, where both you and the professional exchange information and ideas about the best care, medical intervention, or educational program for your child. Information also must be exchanged about the needs of your family and about ways to take advantage of helping patterns that already exist within the family.[48] Both you and the professional need to speak clearly about issues and listen carefully. Indeed, both of you have important expertise to share.

You, for example, have intimate knowledge of your child with special needs; you live with and observe your son or daughter on a daily basis and can contribute invaluable information about his or her routine, development, history, strengths, weaknesses, and so on. To make an accurate diagnosis, determine appropriate therapy or other interventions, and understand both your child and the needs and resources of your family, the professional needs your perspective and unique insight.

The professional, too, has specialized knowledge to contribute — that of his or her discipline. Often you must rely upon the judgment of the professional in matters that are critical to the well-being of your child, a position that may make you feel on unequal and uncertain footing. How comfortable you feel with the professional, how well you feel that individual relates to your child, and how openly he or she responds to your concerns and input will, in many cases, determine whether you continue to work with the professional or decide to seek the services of another.

Thus, there should be a *mutuality* in the parent/professional relationship. Both parents and professionals need to trust and feel trusted, both need to admit when they do not know or are wrong, and both need to negotiate with each other.[49] Trust, respect, and open communication between parent and professional are, therefore, essential to building a good, working relationship. This can take time to develop and may require effort from both parties. To that end, many parent writers suggest:

- If you are looking for a specialist with whom you can work well, ask other parents of children with disabilities. Often, they can suggest the

name of a good speech or physical therapist, doctor, dentist, surgeon, and so on.

- If you don't understand the terminology a professional uses, ask questions. Say, "What do you mean by that? We don't understand."
- If necessary, write down the professional's answers. This is particularly useful in medical situations when a medication or therapy is to be administered.
- Learn as much as you can about your child's disability. This will assist you with your child, and it can help you participate most fully in the team process.
- Prepare for visits to the doctor, therapist, or school by writing down a list of the questions or concerns you would like to discuss with the professional.

***"You live with and observe your son or daughter on a daily basis and can contribute invaluable information about his or her routine, development, history, strengths, weaknesses, and so on."***

- Keep a notebook in which you write down information concerning your special needs child. This can include your child's medical history, test results, observations about behavior or symptoms that will help the professional do his or her job, and so on. (A loose-leaf notebook is easy to maintain and add information to.)
- If you don't agree with a professional's recommendations, say so. Be as specific as you can about why you don't agree.
- Do whatever informed "shopping around" and "doctor-hopping" are necessary to feel certain you have explored every possibility and potential. As Irving Dickman says, "Shop. Hop. Hope."[50]
- Measure a professional's recommendations for home treatment programs or other interventions against your own schedule, finances, and other commitments. You may not be able to follow all advice or take on one more thing, feeling as Helen Featherstone did when she wrote, "What am I supposed to give up?...There is no time in my life that hasn't been spoken for, and for every fifteen-minute activity that has been added, one has to be taken away."[51] Peggy Finston points out that "most professionals won't be familiar with the sum total of our obligations and will not take it upon themselves to give us permission to quit. This is up to us. It's in our power to make the decision."[52]

In conclusion, it is important that the parent/professional relationship empower the parent to be a full participant in information-gathering, information-sharing, and in decisionmaking. However, it is ultimately up to you to decide what role(s) you want to take in this process and what role(s) you need help with. It is helpful to know that families do, indeed, choose different roles in relationship to professionals. Some parents want to allow professionals to make most decisions about their child, others want to serve as an informant to the professional, some want veto power, and some parents want a shared role in the intervention with their child.[53]

You are also free to change your mind about the role or level of involvement you may want or be able to assume regarding your child's services. You may find that you choose different roles at different times for different purposes. Be as direct as possible about what you want or don't want to take on in this regard.

## Addressing Financial Concerns

The expenses associated with raising children can stretch a family's resources. When a child has a disability, particularly one that involves high-priced medical care, a family can quickly become overwhelmed financially. While it is often difficult to resolve financial concerns completely, there are a number of things parents can do that may help. Charlotte Thompson recommends that, as soon as parents find out that their child has a disability, two actions should be taken immediately. These are:

- Start a program to organize and manage your new financial demands. "This not only means management of everyday money, but it also means keeping very careful track of your medical bills and payments."[54] There are a number of money management guides available that explain how to do this.
- Seek information about any and all financial assistance programs. "If the state agency caring for handicapped children is contacted *immediately*, it may *be able to assume financial responsibility for your child's care right from the start.*"[55]

Often, so much attention is focused on the provision of health care that doctors and other medical staff may not mention available sources of financial aid. Many states have passed legislation intended to help families of children with a disability address their financial concerns, but parents will need to be "well focused and persistent" to get the answers they need.

Many children with disabilities are eligible to receive Supplemental Security Income (SSI) benefits, based upon their disability. A recent Supreme Court decision *(Sullivan v. Zebley)* has created changes in the eligibility requirements for these benefits. Because of these changes, many more children are now eligible than in the past. Some children who formerly were denied benefits (i.e., after January 1, 1980) may even be eligible for back benefits. Income limits for families who have a child with a disability can be over $21,500 a year, with total family resources of $5,000 for a two-parent, one-child family. Larger families have higher income limits. Therefore, it is a good idea for all families with a child who is blind or who has a disability to apply for SSI. If a child is found eligible for SSI, he or she is automatically eligible for Medicaid benefits,

even if the family income is higher than what is traditionally required for Medicaid in that state. This is very important for children with disabilities who may have many medical needs.[56]

If your child qualifies for Medicaid, most early intervention services can be paid for by Medicaid. If your child qualifies for Medicaid, it is important to have him or her assessed by a provider qualified to perform the Early Periodic Screening, Diagnostic, and Treatment (EPSDT) program. If an EPSDT program determines that your child has a condition that requires treatment because of "medical necessity," then it can be paid for by Medicaid. Furthermore, each state has a "Child Find" system, which is responsible for locating and assessing children with disabilities. This is required to be free by Federal law. But sometimes, even though there is not supposed to be a waiting list, it can take a long time to get your child assessed. Therefore, it is important to know about what other resources can be used to get help for your child.

Private insurance benefits are one such resource. Usually, nursing, physical therapy, psychological services, and nutrition services can be reimbursed by private insurance. In some cases, occupational therapy and speech therapy are also reimbursable. Educational expenses related to a child's disability are only rarely covered by insurance. However, it is useful to keep track of educational expenses, because these are deductible on your Federal income tax returns.

Some additional resources to contact in your search for financial assistance include:

- Hospital social workers;
- Public health department;
- Public health nurses;
- Volunteer agencies;
- Disability organizations; and
- State government agencies (usually listed under "State Government" in the telephone book), particularly those departments that oversee programs for children with disabilities.

Because searching for assistance may involve a lot of telephone calls, it is a good idea to have paper and pen at hand to record the names and telephone numbers of all those you contact, as well as any referrals they give you. Whether or not you believe your income is too high for your family to quality for financial aid:

> *...the key is to keep trying — to get more information, to follow up leads, and to continue applying for various types of financial assistance. This may seem like an endless paperwork maze to you, but with luck some of the paper at the end will be the green kind that can help you pay your child's medical bills. Keep at it.*[57]

***"Many children with disabilities are eligible to receive SSI benefits, based upon their disability."***

## Future Planning

It is not possible for parents to imagine all the stops and detours that they will make as their unexpected journey takes them into the future. But you will probably be thinking at different times about what the future holds for your child. Advocates believe it is important for parents to have expectations about what their child with disabilities can achieve in the future and to encourage their child to develop as much independence as possible, given the nature and severity of the disability.[58]

Over the past 20 years, the options for children and adults with disabilities have greatly expanded. Schools have developed specialized educational techniques to promote learning and the acquisition of functional skills that will enable individuals with disabilities to have choices about where they live, work, and play, and who they have as friends. The movement to include individuals with disabilities in the mainstream of school life is growing, with significant pressure coming from parents. The premise behind inclusion is that individuals with disabilities should not be segregated but, rather, should have the same opportunities that individuals without disabilities have — that is, the same opportunities to go to neighborhood schools, to be educated alongside their nondisabled peers, to participate as fully as possible in school activities. However, for inclusion to work, school systems must provide each student with supports appropriate to his or her needs. Support, training, and technical assistance also must be made available to teachers and to nondisabled peers. Therefore, it is important for parents to be aware of how inclusion decisions are made in regard to their child and to advocate for supports they feel their child, his or her teacher, and the peer group need in order for the inclusive setting to be a successful one.

Inclusion, however, means more than just including students with disabilities in mainstream school activities. Students will grow up, leave the school setting. What does the future hold for them as adults? This is, naturally, of great concern to parents, disability advocates, disability organizations, and persons with disabilities themselves. For far too long, students have exited the school years to an adult life that lacked opportunities for employment, further education, or community participation.[59] Now, with the help of federal legislation and the advocacy of many concerned parties, adult life for individuals with disabilities holds increasing promise. The Individuals with Disabilities Education Act (IDEA) now requires that school personnel, parents, and each student with disabilities (16 years of age or older, and, in many cases, younger) plan for the student's transition from school to post-school environments, including employment, additional education or training, independent living, and community participation.[60] This legislation is intended to prepare youth with disabilities for the adult world and roles they will encounter upon leaving high school, with the purpose of maximizing their participation in the mainstream of society. Furthermore, the Americans with Disabilities Act (ADA) has incorporated into law provisions that guarantee many of inclusion's principles as individual rights. No longer may most child care centers refuse to serve children because they have a disability. No longer may a qualified individual be denied employment because he or she has a disability. Public accomodations must now be

accessible to all individuals. Many states have been working actively to establish community-based supports so that individuals with disabilities can lead their lives as independently as possible.

Therefore, when you contemplate the future of your son or daughter with disabilities and develop goals for that child, it may be helpful to consider the following suggestions:

- Ensure that your child has the opportunity to acquire skills now that will make him or her as independent as possible in the future.
- Ensure that your child has opportunities to develop social skills that can be used in a variety of settings (regular classroom settings and exposure to many different environments are useful in this regard).
- Write a will that will provide for your child's care and safeguard his or her eligibility for government benefits. (For more information about estate planning, request a free copy of *Estate Planning* from NICHCY.) Some states now provide for self-sufficiency trusts which allow parents to leave money to a child with a disability without disqualifying that child (even of adult age) from government benefits. Other states require that a special needs trust be established.
- Teach your child to be responsible for his or her own personal needs (e.g., self-care, household chores).
- Work with the school and other agencies to ensure that transition planning for your son or daughter takes place and addresses training for future employment, coordination with adult service providers, investigating postsecondary education or training, and participation in community activities.
- Help your child develop self-determination and self-advocacy skills.
- Explore different possibilities for living arrangements once your son or daughter is grown.

### Summary

In this ***News Digest***, we have looked at many of the issues facing you as parents of a child with a disability. Learning that your child has a disability or illness is just the beginning of the journey. At times, you may feel overwhelmed by the challenges associated with disability and by the strength of your own emotions. And while you may feel alone and isolated, there are many supports available. Other parents can be invaluable sources of help and information. Services are also available — early intervention services for young children, educational services for school-aged children, services available through public agencies that can assist your entire family. Having access to information and supports may be critical in maintaining a stable and healthy family life.

To this end, we urge you to read, to talk to other parents who have a child with a disability, to talk with each other and with other family members, and to reach out for assistance when you need it.

We conclude with the words of Clare Claiborne Park, as she reflects upon the experience and emotions of being a parent of a child with disabilities.

> *This experience we did not choose, which we would have given anything to avoid, has made us different, has made us better. Through it we have learned the lesson of Sophocles and Shakespeare — that one grows by suffering. And that too is Jessy's gift. I write now what fifteen years past I would still not have thought possible to write; that if today I was given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands — because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love.*[6]

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# FYI: Information Resources from NICHCY's Database

The publications and organizations listed below, as well as the resources listed throughout this ***News Digest***, are only a few of the many that can provide information to parents and families about issues related to disability. Additional support is also available from state and local parent groups, as well as from state and local affiliates of many major disability organizations.

***To assist you in obtaining documents listed in this issue, you will find the names, addresses, and telephone numbers of publishers on page 22***. If you experience difficulty in locating a document or an organization, please contact NICHCY.

## PRINT MATERIALS
## (Not Specific to a Particular Disability)

### General Parent Readings


Baker, B.L., & Brightman, A.J. (1989). *Steps to independence: A skills training guide for parents and teachers of children with special needs* (2nd ed.). Baltimore: Paul H. Brookes.

Callanan, C.R. (1990). *Since Owen: A parent-to-parent guide for care of the disabled child.* Baltimore, MD: Johns Hopkins University Press.

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Clark, P., Kofsky, H., & Lauruol, J. (1989). *To a different drumbeat: A practical guide to parenting children with special needs.* East Chatham, NY: Alliance for Parental Involvement in Education.

Duffy, S., McGlynn, K., Mariska, J., & Murphy, J. (1987). *Acceptance is only the first battle: How some parents of young handicapped children have coped with common problems.* Missoula, MT: Montana University Affiliated Program.

Featherstone, H. (1980). *A difference in the family: Life with a disabled child.* New York: Basic Books.

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Finston, P. (1990). *Parenting plus: Raising children with special health needs.* New York: Dutton.

Goldfarb, L., Brotherson, M.J., Summers, J.A., & Turnbull, A. (1986). *Meeting the challenge of disability: A family guide.* Baltimore: Paul H. Brookes.

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Kushner, H.S. (1989). *When bad things happen to good people.* New York: Random House.

Larson, G., & Kahn, J.A. (1991). *Special needs - special solutions: How to get quality care for a child with special health needs.* St. Paul, MN: Lifeline Press.

Levin, T. (1992). *Rainbow of hope: A guide for the special needs child.* North Miami Beach, FL: Starlight.

Lindemann, J.E., & Lindemann, S.J. (1988). *Growing up proud: A parent's guide to the psychological care of children with disabilities.* New York: Warner Books.

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Moore, C. (1990). *A reader's guide for parents of children with mental, physical, or emotional disabilities* (3rd ed.). Rockville, MD: Woodbine House.

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Pueschel, S., Bernier, J., & Weidenman, L. (1988). *The special child: A sourcebook for parents and children with developmental disabilities.* Baltimore: Paul H. Brookes.

Ripley, S. (1990). *A parent's guide to doctors, disabilities, and the family.* McLean, VA: NICHCY.

Ripley, S. (1993). *A parent's guide to parent groups.* McLean, VA: NICHCY.

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Simon, R. (1987). *After the tears: Parents talk about raising a child with a disability.* Orlando, FL: Harcourt Brace Jovanovich.

Thompson, C.E. (1986). *Raising a handicapped child: A helpful guide for parents of the physically disabled.* New York: Ballantine Books.

Turnbull, A.P., Turnbull III, H.R., Bronicki, G.J., Summers, J.A., & Roeder-Gordon, C. (1989). *Disability and the family: A guide to decisions for adulthood.* Paul H. Brookes.


### Infants/Toddlers/Early Intervention Services


Brown, W., Thurman, S.K., & Pearl, L.F. (1993). *Family-centered early intervention with infants and toddlers: Innovative cross-disciplinary approaches.* Baltimore, MD: Paul H. Brookes.

Harrison, H., & Kositsky, A. (1983). *The premature baby book: A parents' guide to coping and caring in the first years.* New York: St. Martin's.

Healy, A., Keesee, P.D., & Smith, B.S. (1989). *Early services for children with special needs: Transactions for family support* (2nd ed.). Baltimore, MD: Paul H. Brookes.

Johnson, B.H., McGonigel, M.J., & Kaufmann, R.K. (1991). *Guidelines and recommended practices for the Individualized Family Service Plan* (2nd ed.). Bethesda, MD: Association for the Care of Children's Health.

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Segal, M. (1988). *In time and with love: Caring for the special needs baby.* New York: Newmarket.

## Parent/Professional Partnership

Gargiulo, R.M. (1985). *Working with parents of exceptional children: A guide for professionals.* Boston: Houghton Mifflin.

Levy, J.M., Levy, P.H., & Nivin, B. (Eds.). (1989). *Strengthening families: New directions in providing services to people with developmental disabilities and their families.* New York: Young Adult Institute and Workshop, Inc.

Turnbull, A.P., & Turnbull III, H.R. (1990). *Families, professionals, and exceptionality: A special partnership* (2nd ed.). Columbus, OH: Merrill.

## Siblings and Grandparents

Ambler, L. (Ed.). (1988). Children with disabilities: Understanding sibling issues. *NICHCY News Digest,* Number 11, 1-12.

Epilepsy Foundation of America. (1992). *Brothers and sisters: A guide for families of children with epilepsy.* Landover, MD: Author.

Lobato, D.J. (1990). *Brothers, sisters, and special needs: Information and activities for helping young siblings of children with chronic illness and developmental disabilities.* Baltimore: Paul H. Brookes.

McCaffrey, F.D., & Fish, T. (1989). *Profiles of the other child: A sibling guide for parents.* Columbus, OH: Nisonger Center.

Meyer, D.J., & Vadasy, P.F. (1987). *Grandparent workshops: How to organize workshops for grandparents of children with handicaps.* Seattle, WA: University of Washington Press.

Meyer, D.J., Vadasy, P.F., & Fewell, R.R. (1985). *Living with a brother or sister with special needs: A book for sibs.* Seattle: University of Washington Press.

Meyer, D.J., Vadasy, P.F., & Fewell, R.R. (1986). *Sibshops: A handbook for implementing workshops for siblings of children with special needs.* Seattle: University of Washington Press.

Pinkava, M.J. (1991). *A handful of hope: Helpful suggestions for grandparents of children with disabilities.* Phoenix, AZ: Pilot Parent Partnerships, Inc.

Powell, T., & Gallagher, P.A. (1993). *Brothers and sisters: A special part of exceptional families* (2nd ed.). Baltimore, MD: Paul H. Brookes.

Thompson, M. (1992). *My brother Matthew.* Rockville, MD: Woodbine. (Intended for siblings, grades K-5.)

## Special Education and Related Services

Anderson, W., Chitwood, S., & Hayden, D. (1990). *Negotiating the special education maze: A guide for parents and teachers* (2nd ed.). Rockville, MD: Woodbine.

Arena, J. (1989). *How to write an I.E.P.* (rev. ed.). Novato, CA: Academic Therapy.

Community Alliance for Special Education. (1991). *Special education rights and responsibilities* (rev. ed.). (Available from Special Needs Project, 1482 East Valley Road, #A-121, Santa Barbara, CA 93108. Telephone: (805) 565-1914; for orders, call 1-800-333-6867.)

Cutler, B.C. (1993). *You, your child, and "special" education: A guide to making the system work.* Baltimore, MD: Paul H. Brookes.

Des Jardins, C. (1993). *How to get services by being assertive.* Chicago, IL: Family Resource Center on Disabilities.

Ferguson, S., & Ripley, S. (1991). Special education and related services: Communicating through letter writing. *A Parent's Guide, II*(1), 1-20.

Giangreco, M.F., Cloninger, C.J., & Iverson, V.S. (1993). *Choosing options and accommodations for children: A guide to planning inclusive education.* Baltimore, MD: Paul H. Brookes.

Horne, R.L. (1991). The education of children and youth with special needs: What do the laws say? *NICHCY News Digest, 1*(1), 1-16.

Küpper, L. (Ed.) (1993). Questions and answers about the IDEA. *NICHCY News Digest, 3*(2), 1-16.

Larson, G. (Ed.). (1988). *Managing the school-age child with a chronic health condition: A practical guide for schools, families, and organizations.* Wayzata, MN: DCI Publishing.

Martin, R. (1991). *Parents in the special education process* (a 3-videotape series). Urbana, IL: Carle Center for Health Law and Ethics.

*Questions often asked about special education services.* (1992). McLean, VA: NICHCY.

Parent Advocacy Coalition for Educational Rights. (1992). *Parents can be the key...to an appropriate education for their child with disabilities.* Minneapolis: Author.

Smith-Davis, J., & Littlejohn, W. (1991). Related services for school-aged children with disabilities. *NICHCY News Digest, 1*(2), 1-24.

Wilson, N.O. (1992). *Optimizing special education: How parents can make a difference.* New York: Insight Books.

# PRINT MATERIALS
# (Specific Disabilities)

## Asthma

Plaut, T.F. (1988). *Children with asthma: A manual for parents.* Amherst, MA: Pedipress.

Plaut, T.F. (1991). *One minute asthma: What parents need to know.* Amherst, MA: Pedipress.

## Attention Deficit Hyperactivity Disorder (ADHD)

Fowler, M.C. (1990). *Maybe you know my kid: A parent's guide to identifying, understanding, and helping your child with ADHD.* New York: Birch Lane Press.

Fowler, M.C. (1991, September). Attention deficit disorder. *NICHCY Briefing Paper,* 1-8.

Moss, D. (1989). *Shelley, the hyperactive turtle.* Rockville, MD: Woodbine. (Intended for children aged 4-8.)

Taylor, J.F. (1990). *Helping your hyperactive child.* Rocklin, CA: Prima.

## Autism

Hart, C.A. (1993). *A parent's guide to autism: Answers to the most common questions.* New York: Pocket Books.

Powers, M.D. (Ed.). (1989). *Children with autism: A parents' guide.* Rockville, MD: Woodbine.

Wheeler, M., Rimstidt, S., Gray, S., & DePalma, V. (1991). *Facts about autism.* Bloomington, IN: Indiana Resource Center for Autism.

## Cerebral Palsy

Geralis, E. (Ed.). (1991). *Children with cerebral palsy: A parents' guide.* Rockville, MD: Woodbine.

Weiss, S. (1993). *Each of us remembers: Parents of children with cerebral palsy answer your questions.* Washington, DC: United Cerebral Palsy Associations, Inc.

## Deafness/Hearing Impairment

Bradford, T. (1991). *Say that again, please! Insights in dealing with a hearing loss.* Dallas, TX: Author. (Available from Thomas H. Bradford, P.O. Box 12206-Trust, Dallas, TX 75225. Attention: Ms. Carol Preston.)

Luterman, D.M. (1991). *When your child is deaf: A guide for parents.* Parkton, MD: York Press.

Schwartz, S. (Ed.). (1987). *Choices in deafness: A parents' guide.* Rockville, MD: Woodbine.

## Down Syndrome

Berkus, C.W. (1992). *Charlsie's chuckle.* Rockville, MD: Woodbine. (About a child with Down syndrome, this book is intended for grades K-6.)

Cloud, H.H., & Drews, J. (1993). *Nutrition and fitness for children with Down syndrome: A guide for parents.* Rockville, MD: Woodbine.

Kumin, L. (1993). *Communication skills in children with Down syndrome: A guide for parents.* Rockville, MD: Woodbine.

Pueschel, S.M. (Ed.). (1990). *A parent's guide to Down syndrome: Toward a brighter future.* Baltimore, MD: Paul H. Brookes.

Squires, A.F., & Squires, A.C. (1990). *Down syndrome: Now what do I do?* Sandston, VA: Indian Orchard.

Stray-Gundersen, K. (Ed.). (1986). *Babies with Down syndrome: A new parents' guide.* Rockville, MD: Woodbine.

Trainer, M. (1991). *Differences in common: Straight talk on mental retardation, Down syndrome, and life.* Rockville, MD: Woodbine.

Van Dyke, V., Mattheis, P., Eberly, S., & Williams, J. (Eds.). (1993). *Medical and surgical care for children with Down syndrome: A guide for parents.* Rockville, MD: Woodbine.

## Epilepsy

Freeman, J.M., Vining, E.P.G., & Pillas, D.J. (1990). *Seizures and epilepsy in childhood: A guide for parents.* Baltimore, MD: John Hopkins University Press.

Moss, D. (1989). *Lee, the rabbit with epilepsy.* Rockville, MD: Woodbine. (Intended for children aged 4-8.)

Reisner, H. (Ed.). (1988). *Children with epilepsy: A parents guide.* Rockville, MD: Woodbine.

## Learning Disabilities

Cummings, R., & Fisher, G. (1993). *The survival guide for teenagers with LD (learning differences).* Minneapolis, MN: Free Spirit.

Dunn, K.B., & Dunn, A.B. (1993). *Trouble with school: A family story with learning disabilities.* Rockville, MD: Woodbine. (Intended for students in grades 1-5 and their parents.)

Huston, A.M. (1992). *Understanding dyslexia.* Lanham, MD: Madison Books.

Küpper, L. (Ed.). (1992, April). Reading and learning disabilities: A resource guide. *NICHCY Briefing Paper,* 1-12.

Silver, L.B. (1991). *The misunderstood child: A guide for parents of children with learning disabilities* (2nd ed.). New York: McGraw Hill.

Smith, S.L. (1981). *No easy answers: The learning disabled child.* New York: Bantam.

## Mental Retardation

Smith, R. (Ed.). (1993). *Children with mental retardation: A parents' guide.* Rockville, MD: Woodbine.

Trainer, M. (1991). *Differences in common: Straight talk on mental retardation, Down syndrome, and life.* Rockville, MD: Woodbine.

## Medical Books


Batshaw, M.L. (1991). *Your child has a disability: A complete sourcebook of daily and medical care.* Boston: Little, Brown.

Batshaw, M.L., & Perret, Y.M. (1992). *Children with disabilities: A medical primer* (3rd ed.). Baltimore, MD: Paul H. Brookes.


## Other Disabilities


Barr, A., & Barr, G. (Eds.). (in press). *Children with Fragile X syndrome: A parents' guide.* Rockville, MD: Woodbine.

Bloom, B.A., & Seljeskog, E.S. (1988). *A parent's guide to spina bifida.* Minneapolis, MN: University of Minnesota Press.

Brewer, E.J., & Angel, K.C. (1992). *Parenting a child with arthritis: A practical, emphathetic guide to help you and your child live with arthritis.* Los Angeles: Lowell House.

Dorris, M. (1989). *The broken cord: A family's ongoing struggle with fetal alcohol syndrome.* San Francisco: Harper Collins.

Haerle, T. (Ed.). (1992). *Children with Tourette Syndrome: A parents' guide.* Rockville, MD: Woodbine.

Hochstadt, N.J., & Yost, D.M. (Eds.). (1991). *The medically complex child: The transition to home care.* New York: Harwood Academic.

Holbrook, M.C. (Ed.). (in press). *Children with visual impairments: A parents' guide.* Rockville, MD: Woodbine.

Hughes, B.K. (1990). *Parenting a child with traumatic brain injury.* Springfield, IL: Charles C. Thomas.

Jones, M.L. (1985). *Home care for the chronically ill or disabled child: A manual and sourcebook for parents and professionals.* New York: Harper & Row. (Available from Special Needs Project, 1482 East Valley Road, #A-121, Santa Barbara, CA 93108. Telephone: (805) 565-1914; for orders, call 1-800-333-6867.)

Loring, G. (1991). *Parenting a child with diabetes: A practical, empathetic guide to help you and your child live with diabetes.* Los Angeles: Lowell House.

Maddox, S. (in press). *Spinal network: The total resource for the wheelchair community* (2nd ed.). Boulder, CO: Spinal Network.

McElroy, E. (1988). *Children and adolescents with mental illness: A parents' guide.* Rockville, MD: Woodbine House.

Moller, J.H., Neal, W.A., & Hoffmann, W.R. (1988). *A parent's guide to heart disorders.* Minneapolis, MN: University of Minnesota Press.

Moller, K.T., Starr, C.D., & Johnson, S.A. (1989). *A parent's guide to cleft lip and palate.* Minneapolis, MN: University of Minnesota Press.

Prensky, A., & Palkes, H. (1982). *Care of the neurologically handicapped child.* New York: Oxford University Press.

Project School Care, Children's Hospital. (1992). *Working toward a balance in our lives: A booklet for families of children with disabilities and special health care needs.* Boston, MA: Author.

Williamson, G.G. (Ed.). (1987). *Children with spina bifida: Early intervention and preschool programming.* Baltimore, MD: Paul H. Brookes.


## *Magazines and Newsletters*

*The Bond* - Intended for siblings and adult children of individuals with mental illness, this newsletter is published 4 times a year by the Sibling and Adult Children Network, National Alliance of the Mentally Ill, 2101 Wilson Boulevard, Suite 302, Arlington, VA 22201. Telephone: (703) 524-7600. Price: $10.00/year.

*Coalition Quarterly* - Technical Assistance for Parent Programs (TAPP) Network, Federation for Children with Special Needs, 95 Berkeley Street, Suite 104, Boston, MA 02116. Telephone: 1-800-331-0688 (in MA); (617) 482-2915. Published quarterly, free.

*Exceptional Children* - Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589. Telephone: (703) 620-3660. Published 6 times a year. Non-members, $45.00; Members, $14.00.

*Exceptional Parent* - Psy-Ed Corporation, P.O. Box 3000, Department EP, Denville, NJ 07834. Published 9 times a year. Cost: $18.00. New subscriptions, call: 1-800-247-8080.

*Families and Disability Newsletter* - Beach Center on Families and Disability, Bureau of Child Research, University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045. Telephone: (913) 864-7600. Published 3 times a year, free.

*NASP Newsletter* - National Association of Sibling Programs, Sibling Support Project, Children's Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371. Telephone: (206) 368-4911. Published for service providers.

*Sibling Information Network Newsletter* - Sibling Information Network, A.J. Pappanikou Center, 1776 Ellington Road, South Windsor, CT 06074. Telephone: (203) 648-1205. Published 4 times a year. For members, $8.50; Organizations, $15.00.

*Special Parent/Special Child* - Lindell Press, P.O. Box 462, South Salem, NY 10590.

# ORGANIZATIONS

The organizations listed below are only a few of the many that provide services and information about disability issues to families. When calling or writing an organization, it is always a good idea to be as specific as you can in stating your needs and concerns. For example, state the gender and age of your child, the disability he or she has, and any special needs or interests you have in making your request. This helps organizations provide you with information that is truly helpful and on target.

## *Clearinghouses and Information Centers*

**Clearinghouse on Disability Information** - Office of Special Education and Rehabilitative Services (OSERS), Room 3132, Switzer Building, 330 C Street S.W., Washington, DC 20202-2524. Telephone: (202) 205-8241; (202) 205-8274.

**ERIC Clearinghouse on Disabilities and Gifted Education** - Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589. Telephone: (703) 620-3660.

**HEATH Resource Center** (National Clearinghouse on Postsecondary Education for Individuals with Disabilities) - One Dupont Circle N.W., Suite 800, Washington, DC 200361193. Telephone: 1-800-544-3284 (Voice/TT); (202) 939-9320 (in DC metropolitan area).

**National Center for Education in Maternal and Child Health** - 2000 15th Street North, Arlington, VA 22201-2617. Telephone: (703) 524-7802.

**National Center for Youth with Disabilities** - University of Minnesota, Box 721, 420 Delaware Street S.E., Minneapolis, MN 55455. Telephone: 1-800-333-6293 (Voice); (612) 626-2825; (612) 624-3939 (TT).

**National Clearinghouse on Family Support and Children's Mental Health** - Portland State University, P.O. Box 751, Portland, OR 97207. Telephone: (503) 725-4040; 1-800-628-1696.

**National Health Information Center (ONHIC)** - P.O. Box 1133, Washington, DC 200131133. Telephone: (301) 565-4167; 1-800-336-4797.

**National Information Center on Deafness** - Gallaudet University, 800 Florida Avenue N.E., Washington, DC 20002. Telephone: (202) 651-5051 (Voice); (202) 651-5052 (TT).

**National Information Clearinghouse on Infants with Disabilities and Life-Threatening Conditions,** Center for Developmental Disabilities, University of South Carolina, Benson Building, 1st Floor, Columbia, SC 29208. Telephone: 1-800-922-9234, ext. 201; in South Carolina, 1-800-922-1107.

**National Rehabilitation Information Center (NARIC)** - 8455 Colesville Road, Suite 935, Silver Spring, MD 20910. Telephone: 1-800-346-2742 or 1-800-227-0216 (Voice/TT); (301) 588-9284 (Voice/TT in MD).

## *Technical Assistance to Parent Programs (TAPP) Network:*

National Office: Federation for Children with Special Needs, 95 Berkeley Street, Suite 104, Boston, MA 02116. Telephone: (617) 482-2915 (V/TT).

Regional Offices:

**West Region** - Washington State PAVE, 6316 South 12th Street, Tacoma, WA 98465. Telephone: (206) 565-2266; 1-800-572-7368 (toll-free in WA).

**Midwest Region** - PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417. Telephone: (612) 827-2966 (V/TT); in MN only, 1-800-537-2737 (V/TT).

**Northeast Region** - Parent Information Center, P.O. Box 1422, Concord, NH 03302. Telephone: (603) 224-7005.

**South Region** - Parents Educating Parents Project, Georgia Arc, 1851 Ram Runway, Suite 104, College Park, GA 30337. Telephone: (404) 761-3150.

## *Government Agencies*

**Administration on Developmental Disabilities** - U.S. Department of Health and Human Services, 200 Independence Avenue S.W., Washington, DC 20201. Telephone: (202) 6906590.

**National Council on Disability** - 1331 F St. N.W., Washington, DC 20004-1107. Telephone: (202) 267-3846.

**Office of Indian Education Programs, Bureau of Indian Affairs (BIA)** - MS 3512-MIB, 18th and C Streets N.W., Washington, DC 20245. Telephone: (202) 343-3559.

## *Other Organizations*

**The Arc** (formerly the Association for Retarded Citizens of the United States) - 500 East Border Street, Suite 300, Arlington, TX 76010. Telephone: (817) 261-6003.

**Association for the Care of Children's Health** - 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814-3015. Telephone: (301) 654-6549.

**Association for Persons with Severe Handicaps (TASH)** - 11201 Greenwood Avenue North, Seattle, WA 98113. Telephone: (206) 361-8870.

**Beach Center on Families and Disability** - Bureau of Child Research, University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045. Telephone: (913) 864-7600.

**Council for Exceptional Children,** 1920 Association Drive, Reston, VA 22091-1589. Telephone: (703) 620-3660.

**March of Dimes Birth Defects Foundation** - 1275 Mamaroneck Avenue, White Plaines, NY 10605. Telephone: (914) 428-7100.

**National Clearinghouse on Women and Girls with Disabilities** - 114 East 32nd Street, Suite 701, New York, NY 10016. Telephone: (212) 725-1803.

**National Parent Network on Disabilities** - 1600 Prince Street, #115, Alexandria, VA 22314. Telephone: (703) 684-6763.

**Sibling Information Network** - A.J. Pappanikou Center, 1776 Ellington Road, South Windsor, CT 06074. Telephone: (203) 648-1205.

**Sibling Support Project** - Children's Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371.

**Sick Kids (need) Involved People (SKIP)** - 990 Second Avenue, 2nd Floor, New York, NY 10022. Telephone: (212) 421-9160; (212) 421-9161.

**Zero to Three/National Center for Clinical Infant Programs** - 2000 14th Street North, Suite 380, Arlington, VA 22201-2500. Telephone: (703) 528-4300 (Voice); (703) 528-0419 (TT).

### *Disability-Specific Organizations*

The list of all available disability-specific organizations is far too extensive to print in this ***News Digest***. Many of these organizations are listed on NICHCY's disability fact sheets. Fact sheets are available on the following disabilities:

| | |
|---|---|
| Autism and PDD | Mental Retardation |
| Cerebral Palsy | Severe and/or Multiple Disabilities |
| Deafness | Speech and Language Impairments |
| Down Syndrome | Spina Bifida |
| Emotional Disturbance | Traumatic Brain Injury |
| Epilepsy | Visual Impairments |
| Learning Disabilities | Attention Deficit Disorder |

If you are interested in contacting a disability-specific organization that addresses the needs and concerns of individuals with one of these disabilities, please contact NICHCY and request the fact sheet of interest to you. The sheet will contain the names, addresses, and telephone numbers of organizations providing information and/or services regarding that particular disability.

If you have need of information on a disability that is not addressed through a NICHCY fact sheet, please contact NICHCY, and we will try to put you in contact with an organization that provides services and/or information about the disability of concern to you.

# LIST OF PUBLISHERS

The publishers listed below (in alphabetical order) are only some of the many that provide information to parents about disability issues. Journals are listed at the end, also alphabetically. We present this list of names, addresses, and telephone numbers to help readers obtain the resources listed throughout this ***News Digest.*** If you are interested in obtaining any of the resources we've listed, it's a good idea to contact the publisher and find out the latest payment and ordering procedures. These addresses and phone numbers are, of course, subject to change without notice.

**Academic Chicago Publications,** 2213 W. Institute Place, Chicago, IL 60610. Telephone: 1800-248-7323.

**Academic Therapy Publications,** 20 Commercial Boulevard, Novato, CA 94949. Telephone: (415) 883-3314.

**Alliance for Parental Involvement in Education (ALLPIE),** P.O. Box 59, East Chatham, NY 12060-0059. Telephone: (518) 392-6900.

**American Occupational Therapy Association,** 1383 Piccard Drive, Rockville, MD 208504375. Telephone: (301) 948-9626.

**Association for the Care of Children's Health,** 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814-3015. Telephone: (301) 654-6549.

**Ballantine Books:** Contact the Special Needs Project, 1482 East Valley Road, #A-121, Santa Barbara, CA 93108. Telephone: (805) 565-1914; for orders, call 1-800-333-6867.

**Bantam Books,** 1540 Broadway, New York, NY 10036. Telephone: (212) 354-6500 or 1-800-223-6834.

**Basic Books:** Contact Special Needs Project, 1482 East Valley Road, #A-121, Santa Barbara, CA 93108. Telephone: (805) 565-1914; for orders, call 1-800-333-6867.

**Birch Lane Press,** 120 Enterprise Avenue, Seacaucus, NJ 07094. Telephone: 1-800-447-2665.

**Carle Center for Health Law and Ethics**: Contact Baxley Media Group, 110 W. Main Street, Urbana, IL 61801. Telephone: (217) 384-4838.

**Charles C. Thomas Publishers,** 2600 S. First Street, Springfield, IL 62794-9265. Telephone: (217) 789-8980.

**DCI Publishing:** Contact Sunrise River Press, 11481 Kost Dam Road, North Branch, MN 55056. Telephone: (612) 583-3239.

**Dutton:** Contact Penguin-USA Books, Box 999, Bergenfield, NJ 07621. Telephone: (212) 366-2000 or 1-800-253-6476.

**Epilepsy Foundation of America,** 4351 Garden City Drive, Landover, MD 20785. Telephone: 1-800-332-1000; (301) 459-3700.

**ETR Associates,** P.O. Box 1830, Santa Cruz, CA 95061-1830. Telephone: (408) 438-4060; 1-800-321-4407.

**Exceptional Parent,** 1170 Commonwealth Avenue, Boston, MA 02134. Telephone: (617) 730-5800.

**Family Resource Center on Disabilities,** 20 East Jackson Boulevard, Room 900, Chicago, IL 60604. Telephone: (312) 939-3513; 1-800-952-4199.

**Free Spirit Publishing,** 400 First Avenue North, Suite 616, Minneapolis, MN 55401. Telephone: (612) 338-2068.

**Government Printing Office (GPO),** Superintendent of Documents, Washington, DC 20402. Telephone: (202) 783-3238.

**Guilford Press,** 72 Spring Street, New York, NY 10012. Telephone: 1-800-365-7006.

**Harcourt Brace Jovanovich,** 6277 Sea Harbor Drive, Orlando, FL 32887. Telephone: 1-800-543-1918.

**Harper Collins,** 1160 Battery Street, San Francisco, CA 94111. Telephone: 1-800-328-5125.

**Harwood Academic,** P.O. Box 786, Cooper Station, New York, NY 10276. Telephone: (212) 206-8900.

**Houghton Mifflin,** Wayside Road, Burlington, MA 01803. Telephone: 1-800-225-1464.

**Indian Orchard Publications,** P.O. Box 677, Sandston, VA 23150-0677. Telephone: (804) 226-4731.

**Indiana Resource Center for Autism,** Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Indiana University, Bloomington, IN 47405. Telephone: (812) 855-6508.

**Insight Books,** Division of Plenum Press, 233 Spring Street, New York, NY 10013. Telephone: 1-800-221-9369.

**Interstate Research Associates,** 7926 Jones Branch Drive, Suite 1100, McLean, VA 22102. Telephone: (703) 893-6061.

**John Hopkins University Press,** 701 West 40th Street, Baltimore, MD 21211. Telephone: 1-800-537-5487.

**John Wiley and Sons,** Orders to: Eastern Distribution Center, 1 Wiley Drive, Somerset, NJ 08875-1272. Telephone: 1-800-225-5945.

**Lifeline Press,** 2500 University Avenue, St. Paul, MN 55114. Telephone: (612) 659-9114.

**Little, Brown,** 200 West Street, Waltham, MA 02254. Telephone: 1-800-759-0190.

**Lowell House:** Contact RGA Publishing, 2029 Century Park East, No. 3290, Los Angeles, CA 90067. Telephone: (310) 552-7555, ext. 112.

**Madison Books,** 4720 Boston Way, Lanham, MD 20706. Telephone: (301) 459-5308; 1-800-462-6420.

**McGraw Hill:** Contact McGraw Hill Retail, 13311 Monterey Lane, Blue Ridge Summit, PA 17294. Telephone: (717) 794-5461.

**Mental Health Law Project** (now known as Judge David L. Bazelon Center for Mental Health Law), 1101 Fifteenth Street N.W., Suite 1212, Washington, DC 20005. Telephone: (202) 467-5730.

**Merrill,** Contact Macmillan Publishing Company, 100 Front Street, Box 500, Riverside, NJ 08075-7500. Telephone: 1-800-257-5755.

**Montana University Affiliated Program,** University of Montana, Missoula, MT 59812. Telephone: (406) 243-5467.

**Newmarket Publishing and Communications,** 18 E. 48th Street, New York, NY 10017. Telephone: (212) 832-3579; 1-800-669-3903.

**NICHCY** (National Information Center for Children and Youth with Disabilities), P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-999-5599 (outside DC metropolitan area); (703) 893-6061 (in DC metropolitan area); (703) 893-8614 (TT).

**Nisonger Center**, Publications Office, McCampbell Hall, Room 434, 1581 Dodd Drive, Columbus, OH 43210. Telephone: (614) 292-8365. Ask for the Publications Office.

**Oxford University Press,** 2001 Evans Road, Cary, NC 27513. Telephone: 1-800-451-7556.

**Parent Advocacy Coalition for Educational Rights** (PACER Center), 4826 Chicago Avenue South, Minneapolis, MN 55417. Telephone: Outside of MN, (612) 827-2966; in MN, 1-800-537-2237.

**Parent/Professional Publications,** P.O. Box 59730, Chicago, IL 60645. Telephone: (312) 262-8882.

**Paul H. Brookes Publishing Company,** P.O. Box 10624, Baltimore, MD 21285-0624. Telephone: 1-800-638-3775.

**Pedipress,** Inc., 125 Red Gate Lane, Amherst, MA 01002. Telephone: 1-800-344-5864.

**Penguin Books-USA,** Box 999, Bergenfield, NJ 07621. Telephone: (212) 366-2000 or 1-800-253-6476.

**Pilot Parent Partnerships,** Inc., 2150 E. Highland Avenue, Suite 105, Phoenix, AZ 85016. Telephone: (602) 468-3001. In AZ, 1-800-237-3007.

**Pocket Books,** Simon & Schuster, Order Department, 200 Old Tappan Road, Old Tappan, NJ 07675. Telephone:1-800-223-2348 (customer service); 1-800-223-2336 (orders only).

**Prima Publishing & Communications,** P.O. Box 126OJT, Rocklin, CA 95677. Telephone: (916) 624-5718.

**Pro-Ed,** 8700 Shoal Creek Boulevard, Austin, TX 78758. Telephone: (512) 451-3246.

**Project School Care,** Children's Hospital: Contact Children's Hospital, Project School Care, Gardner 6, 300 Longwood Avenue, Boston, MA 02115. Telephone: (617) 735-6714.

**Random House,** 400 Hahn Road, Westminster, MD 21157. Telephone: 1-800-733-3000.

**Simon & Schuster,** Direct Mail Center, Order Processing Department, P.O. Box 11071, Des Moines, IA 50336-1071. Telephone: 1-800-374-1200; (515) 284-6751.

**Spinal Network,** P.O. Box 4162, Boulder, CO 80306. Telephone: 1-800-338-5412.

**St. Martin's Press,** 175 Fifth Avenue, New York, NY 10010. Telephone: 1-800-288-2131 (outside of NY); (718) 984-3398 (inside NY).

**Starlight Publishing Company, Inc.,** 1893 N.E. 164 Street, Suite 100, North Miami Beach, FL 33162. Telephone: (305) 944-8446.

**United Cerebral Palsy Associations, Inc.:** Contact UCPA of California, 1507 21st Street, Suite 204, Sacramento, CA 95814. Telephone: (916) 442-3573. For S. Weiss's book, contact UCPA, 1522 K Street N.W., Suite 1112, Washington, DC 20005. Telephone: (202) 842-1266 (V/TT); 1-800-872-5827 (V/TT).

**University of Iowa:** Contact Campus Stores, The University of Iowa, 100 Oakdale #M105, Iowa City, IA 52242. Telephone: (319) 335-4645.

**University of Minnesota Press,** 2037 University Avenue Southeast, Minneapolis, MN 55414. Telephone: 1-800-388-3863.

**University of Washington Press,** P.O. Box 50096, Seattle, WA 98145-5096. Telephone: (206) 543-4050. Orders only: 1-800-441-4115.

**Warner Books,** Contact Little, Brown, 200 West Street, Waltham, MA 02254. Telephone: 1-800-343-9204.

**Woodbine House,** 5615 Fishers Lane, Rockville, MD 20852. Telephone: Outside of the DC metropolitan area, call 1-800-843-7323; call (301) 468-8800 in DC metropolitan area.

**York Press,** P.O. Box 504, Timonium, MD 21094. Telephone: (410) 560-1557.

**Young Adult Institute and Workshop,** Inc., 460 West 34th Street, New York, NY 10001. Telephone: (212) 563-7474.

## Journals

*American Journal of Orthopsychiatry,* 19 W. 44th Street, New York, NY 10036-6096. Telephone: (212) 354-7700.

*NICHCY Briefing Paper* - Contact NICHCY, P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-999-5599 (outside of DC area); (703) 893-6061 (in DC area); (703) 893-8614 (TT).

*NICHCY News Digest* - Contact NICHCY, P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-999-5599 (outside of DC area); (703) 893-6061 (in DC area); (703) 893-8614 (TT).

*NICHCY Transition Summary* - Contact NICHCY, P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-999-5599 (outside of DC area); (703) 893-6061 (in DC area); (703) 893-8614 (TT).

*Parent's Guide* - Contact NICHCY, P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-999-5599 (outside of DC area); (703) 893-6061 (in DC area); (703) 893-8614 (TT).

*Topics in Early Childhood Special Education* - Contact Pro-Ed, 8700 Shoal Creek Boulevard, Austin, TX 78758. Telephone: (512) 451-3246.

*News Digest* is published three times each year. Individual subscriptions in the United States are free. In addition, **NICHCY** disseminates other materials and can respond to individual requests. Single copies of **NICHCY** materials and information services are provided free of charge. For further information and assistance, or to receive a *NICHCY Publications List*, contact **NICHCY**, P.O. Box 1492, Washington, DC 20013, or call 1-800-999-5599 (Toll-free, except in the DC Area); (703) 893-6061 (in the DC Area); (703) 893-8614 (TT).

**NICHCY** thanks our Project Officer, Dr. Sara Conlon, at the Office of Special Education Programs, U.S. Department of Education, for her time in reading and reviewing this document. We also thank the following individuals for their thoughtful review and valuable insights on drafts of this *News Digest*: Susan Duffy, Parent, Writer, and Advocate, Missoula, MT; Theresa Rebhorn, Parent Educational Advocacy Training Center (PEATC), Alexandria, VA; and Ann Gordon, Child Find, Falls Church, VA.

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